

**HOUSE APPROPRIATIONS LABOR, HEALTH AND HUMAN SERVICES,
EDUCATION AND RELATED AGENCIES SUBCOMMITTEE**

STATEMENT REGARDING

FY 2007 APPROPRIATIONS

Submitted By

**COPD FOUNDATION
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ORAL TESTIMONY PRESENTED BY;

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SUMMARY OF RECOMMENDATIONS:

The Foundation requests that the National Institutes of Health, National Heart Lung, and Blood Institute, National Institute of Allergy and Infectious Diseases and National Institute on Aging, increase the investment in Chronic Obstructive Pulmonary Disease and that the Centers for Disease Control and Prevention initiate a federal partnership with the COPD community to achieve the following goals:

- Promotion of basic science and clinical research related to COPD;
- Programs to attract and train the best young clinicians for the care of individuals with COPD;
- Support for outstanding established scientists to work on problems within the field of COPD research;
- Development of effective new therapies to prevent progression of the disease and control symptoms of COPD;
- Expansion of public awareness and targeted detection to promote early diagnosis and treatment.

Mr. Chairman and members of the Subcommittee thank you for the opportunity to submit testimony for the record on behalf of the COPD Foundation.

The COPD Foundation:

Established in 2004, the COPD Foundation has a clear mission: to develop and support programs, which improve the quality of life through research, education, early diagnosis, and enhanced therapy for persons whose lives are impacted by Chronic Obstructive Pulmonary Disease. Chronic obstructive pulmonary disease (COPD) is an umbrella term for a group of lung disorders that result in obstruction to airflow in the lung causing breathlessness. The four diseases classified under COPD are emphysema, chronic bronchitis, refractory asthma, and severe bronchiectasis. The COPD Foundation was established to speed innovations which will make treatments more effective and affordable. It also undertakes initiatives that result in expanded services for COPD patients and improves the lives of patients with COPD through research and education that will lead to prevention and someday a cure for this disease.

The COPD Foundation is led by a diverse Board of Directors that includes patients with COPD, as well as some of the most recognized professionals involved in COPD clinical practice, research and patient care. Under the board's direction, the COPD Foundation has established policies based on industry best practices from the Better Business Bureau's Wise Giving Alliance and the National Health Council in areas of governance, accountability and transparency. The first of the COPD Foundation's research initiatives is a partnership with the Scarborough family for the Richard H. Scarborough Bronchiectasis Research Fund, aimed to support translational research to halt or reverse the airways destruction of bronchiectasis.

COPD: Fourth leading cause of death and rising

Chronic Obstructive Pulmonary Disease (COPD) was the fourth leading cause of death in 2003 based on the Centers for Disease Control and Prevention's final data, which attributes 126,382 deaths to COPD for the year. Given that figure, a person dies of COPD every four minutes, and because of the mechanisms of this devastating disease, he or she slowly suffocates to death over several years as airway obstruction and breathlessness increase. No one knows exactly how many people in the US have this terrible disease, but estimates range from 10-20 million diagnosed with another 10-24 million symptomatic, undiagnosed and at risk.

The decreased ability to breathe causes severe physical and mental disability in afflicted individuals. In a 2004 survey, over 50% of patients said that their disease limited the amount or type of work they were able to do, and of those patients nearly 80% were unable to work at all due to their breathlessness. Many of these individuals would otherwise have the ability to continue working for many years.

COPD caused the US economy 32 billion dollars in 2002 and it is estimated that 600 million people worldwide have the disease.

The Medical Needs of the COPD Community have gone unmet:

While smoking is a predominant cause of COPD it is not the only cause. Other significant factors are second hand smoke, occupational dusts and chemicals, air pollution, and a genetic cause called alpha-1 antitrypsin deficiency.

The other leading causes of death have seen great improvements over the past several decades. While the mortality of COPD rose by 163% from 1965-1998, the mortality of coronary heart disease decreased by 59% and the mortality of stroke decreased by 64%.

And yet this fourth leading cause of death is a hidden, silent killer. There is a lack of awareness among the public that coughing and breathlessness is not a normal sign of aging. Those diagnosed with this disease are quick to blame themselves and are ashamed of their disease because of the current societal stigma. Many lack the information for proper disease self-management, which could easily prevent exacerbations and thusly, many hospital and emergency room visits.

Currently, the only therapy shown to improve survival is supplemental oxygen. There are other therapies that can improve symptoms but they do not alter the natural history of the disease.

Detection:

COPD is fairly easy to detect: in addition to symptoms of breathlessness, cough and sputum production, spirometry is a quantitative test that measures air volume and air flow in the lung and is relatively easy and inexpensive to administer.

COPD Research:

The COPD Foundation believes that significant federal investment in medical research is critical to improving the health of the American people and specifically those affected with COPD. The support of this Subcommittee has made a substantial difference in improving the public's health and well-being. While this is by no means an exhaustive list, the Foundation wishes to recognize and appreciate the efforts of the National Institutes of Health in creating the COPD Clinical Research Network, for conducting a COPD state of the science conference, and launching a national education campaign.

Chronic disease have a profound human and economic toll on our nation. Nearly 125 million Americans today are living with some form of chronic condition. The Foundation recognizes that the Centers for Disease Control and Prevention understands that COPD is one of the only top ten causes of death that is on the increase, however, COPD has not been designated the resources to be a major focus of the CDC. The Foundation urges the Subcommittee to encourage the CDC to expand its data collection efforts and to expand programs aimed at education and prevention of the general public and health care providers.

Specific Areas of Concern and Recommendations:

The Foundation requests that the National Institutes of Health, National Heart Lung, and Blood Institute, National Institute of Allergy and Infectious Diseases and National Institute on Aging, increase the investment in Chronic Obstructive Pulmonary Disease and that the Centers for Disease Control and Prevention initiate a federal partnership with the COPD community to achieve the following goals:

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COPD FAST FACTS

COPD, or Chronic Obstructive Pulmonary Disease, is an umbrella term used to describe progressive lung diseases, encompassing emphysema, chronic bronchitis, refractory asthma, and severe bronchiectasis. This progressive disease is characterized by increasing breathlessness.

- National Heart, Lung and Blood Institute estimates that 12 million adults have COPD and another 24 million are undiagnosed or developing COPD.
- COPD is the fourth leading cause of death in the US, accounting for 126, 382 deaths in 2003.
- COPD kills more women than men each year.
- COPD will be the third leading cause of death in the US by 2020.
- On average, a person with COPD dies every four minutes in the US.
- COPD cost the US economy \$32 billion, in direct and indirect costs in 2002.
- It is estimated that over 600 million people worldwide have COPD.
- Smoking is not the only cause of COPD; second-hand smoke, occupational dust and chemicals, air pollution and genetic factors (such as alpha-1 antitrypsin deficiency) also cause COPD.
- COPD is relatively easy to diagnose using a spirometry machine, where the patient exhales as much as possible through a tube.
- COPD does not have a cure and treatments are only available to help individuals manage their symptoms of COPD.

Common symptoms of COPD include:

Breathlessness

Decreased exercise tolerance

Chronic coughing (with or without mucus)

Wheezing

Tightness in chest

Frequent clearing of the throat